

COMMENTARY

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The Right Not To Know: An Autonomy Based Approach - A Response to Adorno

Dr Adorno and I have corresponded for some time on the question of a right not to know (genetic) information. I enjoyed reading his paper and I am struck by the degree of agreement that we share. We both agree—for example, that unsolicited knowledge can be a burden which can significantly compromise an individual's psychological integrity. We both share a desire to respect individual self determination. Also we each consider it reasonable for individuals to choose not to receive potentially harmful information. I have already made these arguments, and more, elsewhere,¹ but my starting point has not been autonomy, as advocated by Adorno, but rather privacy. In essence, my argument is that individuals enjoy, and are entitled to enjoy, a measure of psychological privacy which can be invaded by unwarranted disclosures of information (Laurie,¹ pp 255–74).

The reason that I prefer privacy to autonomy is not because I have any wish to "deny people the right to self determination"² but rather because I perceive deficiencies in the autonomy model. Indeed, my approach and that of Adorno are not mutually exclusive; it is simply that my approach is broader and encompasses some of the harder cases which an autonomy based approach cannot help us to resolve. Thus, most of the substance of Adorno's approach is subsumed within my model. I have—for example, no disagreement whatsoever with the view that if you have an indication that an individual would not wish to know then this wish should be respected. One might even establish novel means of discerning individuals' wishes by establishing a register to record advance refusals, as Adorno suggests. What should happen, however, if there is no indication of an individual's wishes? In such cases it is not

possible to approach the individual to ask: do you want to know, because, as Fletcher and Wertz poignantly observe: "There is no way...to exercise the choice of not knowing, because in the very process of asking 'Do you want to know whether you are at risk' the geneticist has already made the essence of the information known."³

If I have understood Andorno correctly, his model leaves this dilemma unresolved. His reluctance to adopt a broader approach stems, in part, from the charge that a decision not to disclose taken by a health care professional is paternalistic. To avoid this accusation, Andorno conceptualises his "right not to know" as a means of *enhancement of autonomy*, whereby "the decision to know or not to know is not taken out of the hands of the patient by the doctor". I have three observations about this approach. First, the patient centred focus cannot answer the Fletcher/Wertz scenario. Second, paternalism is not a homogenous practice and not all forms of paternalism are bad.⁴ Paternalism has become a dirty word with the rise in success of the principle of respect for autonomy. The desire to enforce this principle now dominates much ethical and medicolegal discourse, but it is disingenuous at the same time to deny the presence of paternalism and, at times, the value of certain forms of it. Most particularly, it must be recognised that the autonomy model cannot provide ethical and legal solutions to all medical dilemmas and I would argue that we are misguided in trying to make it do so. Finally, there is an irony in Dr Andorno's paper because not only does he recognise a role for paternalism at various junctures, but his argument about enhancement of autonomy, and his defence of conduct directed towards facilitating patient choices is, in itself, a form of paternalism. See—for example: "it is the responsibility of the health care professional to assess the amount of information an individual wants and is able to deal with at a particular time". He also states: "...[I]et us recall that, for those cases in which the interest in not knowing seems clear, but no explicit choice has been made, we already have the concept of 'therapeutic privilege', which allows physicians to withhold information if, based on sound medical judgment, they believe that divulging the information would be harmful to a depressed or unstable patient...".

He also asks "...how can doctors assume that patients' relatives do not have an interest in knowing genetic information, which may be extremely important to them". I would respond that they cannot, nor should they. By the same token, I would add: how can

health care professionals assume that relatives would wish to know? Once again, I would respond that they cannot do so. This is precisely the essence of the dilemma—a health care professional does not know one way or the other what relatives would or would not wish to know.

I do not assume that people do *not* want to know, as Dr Andorno suggests. Indeed, my position is quite the opposite. I challenge any assumptions about people's wishes (Laurie,¹ pp 257–61). I have, in fact, a serious concern about the current preoccupation with autonomy and about its ascendancy to the status of supreme ethical principle in many quarters. I question this on a number of grounds, not least because it is an incomplete answer to many dilemmas and because it leads to limitations on our thinking about how to approach ethical quandaries such as those posed by an interest in not knowing. The limits are expressed by Andorno himself when he states: "...the exercise of an autonomous choice seems necessary for the functioning of the right not to know, because it is impossible to determine a priori the wish of the patient". The latter point may well be true, but Dr Andorno does not then go on to tell us how the harder cases should be dealt with where there is no prior indication of a patient's wishes. His idea of a register is, as he himself admits, of limited utility and should not lead to an assumption that people would want to know. If one accepts that individuals can be harmed by unsolicited disclosures and that some protection for psychological integrity is desirable, it is difficult, then, to draw a meaningful distinction between those who have exercised their autonomy and so enjoy protection and those who have not done so and so fall outside the autonomy based approach.

My privacy model advocates that because we cannot assume anything about what people want in the absence of actual knowledge about their wishes then a measure of caution should be exercised in taking disclosure decisions. Various factors should be weighed in the balance before disclosure is made, including the availability of a therapy or cure, the nature of the disease and its consequences, and any advance statements made by the patient in question, if available (Laurie,¹ pp 261–4). Most specifically, however, there should be recognition of an interest in not knowing. As Dr Andorno correctly identifies, this places the onus to demonstrate that some utility would come of the disclosure, on those who would seek to disclose. The presumption

is that individuals' psychological privacy should be respected unless there is good reason not to do so. Disclosures can be justified both in the interests of the individual herself and her relatives. Prior wishes should be respected but even in their absence a decision not to disclose may be reached to protect the individual's privacy. This is undeniably a paternalistic approach; but the nature of the dilemma necessarily makes it so.

As a final caveat, I would question the use of the language of rights in this context. I myself am guilty of such usage, for it can often be a helpful form of shorthand in discussion. The details and implications of rights discourse sit uneasily, however, in the present circumstances, and for these reasons I agree with Dr Andorno that there should be no legal "right" not to know which can be enforced against family members (Laurie,¹ p 265). A better approach, to my mind, is to talk of the *interest* that individuals might have in not knowing. On this basis, we might find that there is even less disagreement between myself and Dr Andorno.

REFERENCES

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